

Lions Low Vision Rehabilitation Network (Lions LOVRNET) Demonstration Project
EXECUTIVE SUMMARY

*Multiple District 22 Lions Vision Research Foundation and
Lions Vision Research and Rehabilitation Center at the Johns Hopkins Wilmer Eye Institute*

Background

Low vision refers to chronic disabling visual impairments that cannot be corrected with eyeglasses or with medical or surgical treatment. Most low vision in the U.S. is caused by age-related eye diseases, with age-related macular degeneration, diabetic retinopathy, and glaucoma leading the list. Inherited eye diseases are a leading cause of low vision in children and young adults. The most recent estimates indicate that between 4 and 5 million Americans presently have low vision. Eighty percent of Americans with low vision are over age 65. The aging of the U.S. population is accelerating as the baby boomers move into their older years, so the number of people with low vision is expected to double over the next two decades.

Low vision rehabilitation can be highly effective in restoring the ability of visually impaired and blind people to function in everyday life, but the availability of low vision rehabilitation services is grossly inadequate to meet the current need, and no national plan exists to address the growing demand for services. Approximately 60% of people with low vision have visual impairments that preclude reading, driving, and performing fine visual motor tasks, increase the risk of falls and injury and interfere with the person's ability to manage medications and personal hygiene. People with this less severe form of low vision, which is called mild/moderate low vision, can be helped with strong magnifiers matched to their vision requirements, a variety of daily living aids, and with education, both on how to use magnifiers and other assistive devices and how to adjust their activities to adapt to their visual impairments. Although this basic level of low vision rehabilitation, called primary low vision care, is included in optometry school curricula and ophthalmology residency training programs, very few optometrists or ophthalmologists provide any basic low vision services in their practices.

The other 40% of people with low vision have more severe visual impairments, the majority of whom are classified as "legally blind". These people experience major disabilities in performing daily living activities, are unable to travel independently, frequently become socially isolated and physically inactive, are at high risk of injury and declines in physical and mental health, and are at increased risk of hospitalization and/or being admitted to a nursing home. This group of people with low vision requires more extensive rehabilitation services, preferably in the home and community, and they require more assistance and community services.

Service providers who traditionally were professionally prepared in graduate level education programs specializing in the rehabilitation and education of the blind and visually impaired have dramatically reduced in number over the last 10 years. The limited number of graduate programs that currently prepare low vision rehabilitation direct service providers cannot meet even the current

demand for service of blind and visually impaired children and working-age adults, let alone the 4 times larger current geriatric low vision population. Although occupational therapists are considered eligible by third party payers like Medicare to provide comprehensive low vision rehabilitation services to more severely visually impaired people, only a handful have the specialized training needed to work with blind and visually impaired patients.

Lions LOVRNET

The Lions Low Vision Rehabilitation Network (Lions LOVRNET) is a model for a new community-based healthcare program that will address the current shortage and distribution of low vision rehabilitation services and can expand to keep pace with the growth in demand as our population ages. The Lions of Multiple District 22, in partnership with low vision rehabilitation experts at the Lions Vision Research and Rehabilitation Center of the Johns Hopkins Wilmer Eye Institute (Lions Vision Center), is developing and implementing the Lions LOVRNET as a demonstration project in Maryland, Delaware, and the District of Columbia (Multiple District 22). The aims of the Lions LOVRNET are to: 1) train and provide professional consultative support to local optometrists, ophthalmologists, ophthalmic and optometric technicians, occupational therapists, rehabilitation therapists working in the blindness field, and social workers so they can offer low vision rehabilitation services as part of their practices, 2) create a single portal for the low vision rehabilitation system within Multiple District 22 to which ophthalmologists can refer patients or patients can refer themselves, 3) coordinate care by matching patients to appropriate trained service providers in their area, and 4) constantly improve the quality and effectiveness of services by obtaining patient reported outcome measures and using them to provide continuous professional education to the service providers.

Local Lions are a vital part of the Lions LOVRNET. Not only do Lions serve as the primary resource for their blind and visually impaired neighbors who need to be directed to the Lions LOVRNET, but they also are advocates for the Lions LOVRNET with local ophthalmologists and provide ophthalmologists with patient education materials. Lions also are trained to assist blind and visually impaired people in a discrete and safe manner, initiate and facilitate peer support groups, and educate the public in order to combat stereotypes and social stigmas associated with blindness and visual impairments. The goal of the proposed project is to demonstrate how the growing demand for low vision rehabilitation services in the U.S. can be met by the Lions LOVRNET model and disseminate the developed educational resources and programs so that the Lions LOVRNET can be expanded nationwide.

The core Lions LOVRNET project has recently received funding from the Lions Clubs International Foundation SightFirst program and from the Reader's Digest Partners for Sight Foundation. This funding is being used to develop the computer information systems required to operate the network and to measure patient outcomes; to develop and offer online education programs for optometrists, ophthalmologists, occupational therapists, rehabilitation therapists working in the blindness field, social workers and Lions volunteers; to recruit and train low vision rehabilitation service providers (optometrists, ophthalmologists, occupational therapists, rehabilitation therapists, and social workers) to participate in the Lions LOVRNET; and to provide a pathway for patients to acquire affordable low vision care and devices within their home community.

Human Resource Training

The Lions LOVRNET is being built on the principles of continuous education and continuous improvement. The goal of continuous education is to constantly raise the level of foundational knowledge of practicing clinicians as new knowledge is developed, to facilitate interactions between peers so they can learn from each other's experiences, and to provide continuous evaluation of clinical performance with measures of patient outcomes, which are needed to constantly improve the quality and effectiveness of services. The Lions LOVRNET continuous education program targets four groups of healthcare professionals who provide low vision rehabilitation services: 1) optometrists/ophthalmologists (low vision physicians), 2) occupational therapists, 3) social workers, and 4) vision rehabilitation therapists and ophthalmic/optometric technicians. A second Lions LOVRNET training program for lay care-givers and volunteer service providers targets patients' family members, home health aides, and Lions.

The low vision rehabilitation continuous education program for healthcare professionals has four components: 1) didactic education in the form of self-paced online courses and in-person workshops that provide foundational knowledge; 2) mentoring in the form of observing an experienced clinician work with patients, on-site and remote (telementoring) supervision of clinical practice by an experienced clinician, and "just-in-time" information, instructions, and assistance provided online to the clinician on demand (e.g., using e-tablets or smart phones); 3) continuous peer-to-peer education through live online and in-person clinical case conferences and LOVRNET-mediated case consultations (e.g., webinars, online forums); and 4) continuous peer benchmarking and analyses of clinical outcomes combined with outcome-driven peer reviews of clinical methods and clinical decision-making through online and in-person professional conferences.

Training videos for Lions and lay care-givers are being produced and hosted on the lionsvision.org website to teach Lions, patients' family members, and caregivers how to assist low vision patients after they have completed low vision rehabilitation services. One common problem is older low vision patients often forget how to focus their low vision devices, change batteries in stand magnifiers, or operate their video magnifiers. The training videos will teach Lions how to troubleshoot problems experienced by patients with their low vision devices and how to help patients solve different types of low vision device use problems. Another common situation is that the occupational therapist might recommend increasing task lighting, reducing glare from a window, taping down throw rugs to prevent falls, marking stair treads, labeling and organizing food packages in the pantry, changing the color of wall switch or outlet plates to increase contrast, or other modifications of the home environment to make it easier for the patient to perform daily activities and increase safety. The training videos will include lessons on how to make various modifications of the home environment that frequently are recommended by therapists. In addition to training videos, the vision rehabilitation professionals present workshops for Lions to give them first-hand experience with low vision devices and home environment modifications.

The optometrists, ophthalmologists, occupational therapists, social workers, and ophthalmic and optometric technicians are busy health care professionals who cannot take time away from their practices to participate in a full-time training program. However, all of these professionals must engage in continuing professional education activities in order to maintain licensure and/or certification. The Lions LOVRNET training program consists of a series of online lecture-format courses specifically designed for each type of professional. These courses are designed to be completed on the learner's schedule at whatever pace is comfortable.

Operation and Governance of Lions LOVRNET

The Lions Vision Research and Rehabilitation Center (LVRRRC) of the Johns Hopkins Wilmer Eye Institute is partner in the Lions LOVRNET project. The LVRRRC is responsible for the development and integration of the Lions LOVRNET and James Deremeik (a LVRRRC faculty member) is the Lions LOVRNET Project Manager. The professional staff of the LVRRRC and various contractors are responsible for developing and delivering the education program and system software; the LVRRRC professional staff also is responsible for analyzing clinical outcome measures, recruiting and training participating clinicians, and for quality control of low vision rehabilitation service delivery in the network.

The Lions LOVRNET has its executive office at the headquarters of the Blind Industries and Services of Maryland (BISM). BISM is a Lions LOVRNET partner and is providing office space, telephone and computer services, training facilities, and human services assistance to the project at no cost. The Lions LOVRNET executive office is staffed by a full-time Project Administrator and in the second year will be joined by a full-time Administrative Assistant. The executive office is responsible for day-to-day management of Lions LOVRNET patient management and network operations, Lions volunteer training and certification, and providing staff support to the Lions LOVRNET Steering Committee. The Lions LOVRNET executive office also is responsible for managing patient referrals to the network, scheduling telephone interviews of patients by trained and certified Lions volunteers, matching patients to appropriate network clinicians, managing computer-generated patient reports to LOVRNET clinicians and referring physicians, managing the inventory of low vision kits loaned to LOVRNET clinicians, referring patients to trained and certified Lions volunteers who can provide requested in-home follow-up services, and follow-up with patients on delivery of low vision devices.

Oversight of the Lions LOVRNET operations and the LCIF SightFirst grant management is the responsibility of the Lions LOVRNET Steering Committee, which is a committee of the Multiple District 22 Lions Vision Research Foundation (LVRF) and reports to the LVRF Board of Directors. The Steering Committee Co-Chairs are PDG Darlene Travers and PDG Ken Chew. The other members of the Steering Committee consist of two representatives from each District of Multiple District 22. The Steering Committee members are named by the LVRF Board. An Advisory Committee to the Steering Committee consists of representatives of different Lions LOVRNET stakeholders (e.g., LCIF, BISM, Johns Hopkins Wilmer Eye Institute, state professional associations representing Lions LOVRNET service providers, and the Vision Council trade association for the low vision device industry). An Executive Committee including the Co-Chairs, which represent two Districts, and a Steering Committee member for each of the other three Districts meet at least weekly to make decisions on the day-to-day issues presented by the Lions LOVRNET project staff.